

Department of Health and Senior Services

Early Intervention System

Response to Public Comment
on
Family Cost Share

January 20, 2004

Early Intervention System Family Cost Share Proposal

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Summary of Public Comments/Testimony

- The number of people that attended a public hearing - 166.
- The number that presented oral testimony at a hearing - 61.
- The number that submitted written comments (mail, e-mail, public hearing) - 164.
- Summary of individuals providing public comment: Parents (75), Advocate Organizations (12), EIP Providers (17), Regional Early Intervention Collaboratives (REICs) (2), Legislators (5) and Others (relatives, friends, physicians, general public) - (53).
- Most, if not all, of the parent/family members providing public comment were very supportive of the early intervention system and shared stories of how services benefited their children and families.

Major Concerns/Issues Identified by the Public Input

- **The proposed family cost share at the beginning tier level is too low.**
The proposed point to begin a family cost share is at 150% of the federal poverty level (FPL) or \$27,600 for a family of four. Many offering testimony recommended maintaining the level of 350% of the federal poverty level as the starting point for a family cost share or \$64,400 for a family of four. Others offered recommendation to keep as close to the 350% FPL as possible.
- **The proposed family cost share at the upper tiers is too high.**
Concern was expressed that the Department did not take into consideration the cost of living in New Jersey, and felt that those at the higher income levels would opt out of the early intervention system and seek services privately. "NJ has the highest cost of living in the country. The federal poverty level is not adjusted for regional or state variations in the cost of living. Therefore, NJ families that earn the federal poverty level have significantly lower "purchasing power" than families in other less expensive states."
- **Services provided at public expense for the first two hours per week should be maintained.**
A significant number of families were concerned about any charges for early intervention services and how it would affect them financially. A significant number of families reported out of pocket expense or use of insurance to provide services in addition to the two hours per week received through the EIS. If the additional services are identified as needed on the IFSP they would be included in determining the cost of services and the family's cost share.
- **The definition of extraordinary expenses should be expanded.**
Certain expenses associated with medical care for the special needs child or a family member can be deducted when considering family cost share under the proposed changes. Concern was expressed that the list of eligible expenses was not broad enough to account for many expenses that families face in raising a disabled child.

- **Revenue collected would be used to off-set state funds currently budgeted for the EIS.**
 Federal Part C Statute, Subchapter III, 1440, Payer of Last Resort addresses both non-substitution and reduction of benefits that does not permit the state to reduce assistance. The revenue generated from the proposed family cost share will go back into services to support the increased growth and cost of the EIS.
- **Availability and access to other funding resources should be pursued before changing the family cost participation.**
 There is substantial discrepancy between the intent to access other resources and the reality that many states have experienced. Many states have tried and failed for a variety of reasons including the significant complexities of accessing other federal and state funds or mandates and competition within the state for limited resources. While the state will continue to pursue alternative resources such as insurance to support EIS, these other potential resources do not provide an immediate or short term solution to the revenue shortfall for the EIS. In fact, many times access to other resources, such as Title XIX/Medicaid or private insurance, is directly linked to some sort of cost participation on the family's part.
- **Families are concerned that utilization of their private insurance will ultimately have an effect on their overall access to health and medical services for their child**
 Use of private insurance is challenging and must be pursued in a manner that would not adversely impact families. State specific insurance legislation would significantly increase the likelihood of success of generating revenue and protecting families from issues including exhaustion of life time caps, deductibles, co-payments and endless denials and appeals for coverage of early intervention services.
- **The cost of implementing a family cost share collections will off-set revenue collected.**
 The state has proposed a family cost participation system that is designed to generate \$7-9 million dollars annually. The current system is averaging approximately \$400,000 annually. The state has received bid proposals for the establishment of a Central Management Office (CMO) that will support provider enrollment; billing and payment for services; federal reporting requirements; third party billing and collections and provide the data needed to support quality assurance activities including programmatic monitoring and system evaluation. Although part of the CMO, the activities related to the family cost share represents a small percentage of the cost expended to implement the billing and collections. Over 90% of revenues generated from family cost share collections will be used to support the early intervention system.
- **Family cost participation will discourage families from participating in the state's Part C system.**
 The "Utah Parent Participation Impact Study" verified that the "negative predictions that were made about family attrition, stress, and changing relationships between service providers and families are not supported by the survey data." Several states that have implemented family cost participation changes have experienced some families initially opting out of services but they also reported that new referrals continue to increase. The state will conduct reviews to identify policy issues and impact when the family cost share is implemented.

Department of Health and Senior Services Response

- The State will maintain its commitment to early intervention by maintaining financial support of at least the current State FY 04 funding level for the Early Intervention System.
- The State commitment of two hours per week of early intervention services at public expense regardless of income will be eliminated.
- The Department has reviewed the comments concerning expanding the definition of allowable extraordinary expenses and will be publishing revisions to the proposed policy and procedures.
- In the current fiscal climate, the Department finds that it is necessary and allowable under federal regulations to include a family cost share into NJ's "System of Payment" for the early intervention system.
- Pending Federal Office of Special Education Programs approval, the Department intends to begin implementation of the changes in Family Cost Share for March 1, 2004, for all new families entering the system; and phase in the family cost share for existing families over a three month period, through review of their Individual Family Service Plans.
- The Department will continue to explore additional and alternate resources to help support the early intervention system including insurance and waiver programs.
- The Department has thoroughly reviewed and considered the public comment and has revised the proposed policy changes for early intervention to address many of the expressed concerns on the attached chart.

Summary and response to Public Concerns

Issues/concerns	About the Changes	What do the changes mean?
<p>Starting a family cost share at 150% of the federal poverty level is too low.</p> <p>For a family of 4 150% of FPL is \$27,600</p>	<p>The Department has increased the point of initiating the family cost share from 150% of the federal poverty level (FPL) to 350% FPL.</p> <p>Although the sliding scale is progressive; minimum monthly family cost share of \$10 will be charged for any family at or above 350% FPL.</p>	<p>A family below 350% FPL will receive services at public expense.</p> <p>For families above 350% of the FPL there would be a minimum monthly cost share of \$10. This would begin \$42,420 for a family of 2, \$53,410 for a family of 3, \$64,400 for a family of 4, and \$75,390 for a family of 5 etc.</p>
<p>Family cost share is too high at the upper tier levels.</p>	<p>Reductions to the upper tiers of the family cost sharing scale have been made to address the concerns of families, providing a more reasonable monthly cost share for all income levels.</p>	<p>The family cost share for middle, upper middle and upper income levels have all been adjusted downward. As an example: for a family of 4 with an income of \$156,400 the proposed monthly cost share would have been \$442; with the changes the monthly cost share will now be \$194.</p>
<p>Keep system the same by continuing to provide 2 hours of service per week free to families, regardless of income.</p>	<p>The Department will proceed to eliminate the two hours of early intervention services at public expense. This is necessary and allowable under federal regulation and if not implemented may result in the need to reduce costs in other ways such as changing eligibility requirements which would limit the number of children that benefit from early intervention services.</p>	<p>With the elimination of the two hours at public expense, families below 350% of FPL will receive intervention services at public expense.</p> <p>All families, above and below 350% FPL, will continue to receive service coordination, procedural safeguards, developmental evaluations and assessments and the development of the Individualized Family Service Plan at public expense.</p>
<p>The definition of extraordinary expenses</p>	<p>The Department will clearly define</p>	<p>Families will be better able to determine</p>

Issues/concerns	About the Changes	What do the changes mean?
should be expanded.	extraordinary expenses a family may or may not identify to be used to reduce adjusted gross income, thereby reducing a family's cost share.	what, if any, extraordinary expenses will be allowable deductions in determining a family cost share.
The Department is continually looking for additional and alternate resources to help support the early intervention system.	The Department will continue to investigate and pursue discussions regarding mandatory insurance coverage for early intervention services, along with other recommended potential resources.	Families will be offered an opportunity to use their health insurance to help defray the monthly family cost share.
The cost of implementing the family cost share through the central management office will off-set the revenue collected.	The implementation of a central data and finance office provides technical support and services to meet obligations under Part C of the Individuals with Disabilities Education Act (IDEA). The central database brings together demographic, service, and claims-pay/reimbursement information for the full population of children, families and providers in the Early Intervention System. The data will support benefit screening and demographic information that will be used to evaluate and monitor the early intervention system.	Over 90% of the revenue collected will remain with the early intervention system. All families will receive monthly statements explaining services rendered and associated cost.